

INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES
Registration and Review Report

Fiscal Year 2020
July 1, 2019 through June 30, 2020



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FOR:

The DEPARTMENT OF HEALTH AND SOCIAL SERVICES

AND

THE ALASKA LEGISLATURE

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Preface: About the Developmental Disabilities Registration and Review

Under AS 47.80.130 (d), the Department of Health and Social Services (DHSS) is required to maintain a waitlist of persons who experience a developmental disability who would be eligible to receive state-funded services. It is further required that an annual report to the Governor and specified legislative committees be presented when there is not adequate funding to meet the needs of all individuals determined to have a developmental disability. Senior and Disabilities Services (SDS) employs the Developmental Disabilities Registration and Review (DDRR) as the waitlist tool to assess an individual's current service needs. Information provided through the DDRR is used place an individual onto the Registry in score order, to determine who is offered the opportunity to request services through Medicaid's Home and Community Based (HCB) Intellectual/Developmental Disabilities (IDD) waiver. Additionally, SDS has a second waiver for individuals who experience a developmental disability and have less intensive needs, called the Individualized Supports Waiver (ISW), but that waiver has not yet reached capacity.

The DDRR provides predictive information the State of Alaska (SOA) uses for program planning and management. The DDRR provides the State and other stakeholders with information on the current needs and preferences of the individuals and families waiting for expanded support services.

When an individual requests placement on the Registry they can indicate an interest in being considered for the ISW, IDD waiver, or both waivers. A separate waitlist for services for the ISW will be utilized when the program has reached capacity (has 600 participants in active status).

Cost projections included in this report should be considered estimates to use in planning, rather than computation of the actual cost of comprehensive services that would be necessary to meet the needs of everyone on the list.

Section 1: The Purpose of the Developmental Disabilities Registration and Review (AS 47.80.130(d) (1))

The Registry assists Senior and Disabilities Services in planning for the future needs of individuals who have a developmental disability. Additionally, the Registry is used to select individuals for enrollment in waiver services when resources are available. To ensure SDS has accurate and current information about needs, SDS requests that individuals on the Registry update information about changes in their condition or family circumstances at least annually.

To be eligible to be placed on the Registry, an individual must have a developmental disability as defined under the provisions of AS 47.80.900 (6). “Person with developmental disability” means a person who is experiencing a severe, chronic disability that:

- Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- Is manifested before the individual attains age 22;
- Is likely to continue indefinitely;
- Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency; and
- Reflects the person’s need for a combination and sequence of special, interdisciplinary, or generic assistance, supports, or other services that are of lifelong or extended duration and are individually planned and coordinated.

Section 2: Placement on the Registry and the Criteria for Ranking and Selection (AS 47.80.130 (d)(2))

For an individual to be included on the Registry, they must complete an Eligibility Determination application:

http://dhss.alaska.gov/dsds/Documents/SDSforms/DD_Determination_Application.pdf

The application for determination of developmental disability provides SDS the information needed to determine whether the applicant meets the standard outlined in AS 47.80.900(6). If an individual is determined to have a developmental disability, the

individual/guardian is notified in writing. The approval letter contains information about the next step of completing the DDDR, to be considered for long-term supports.

Questions on the DDDR are designed to gather information about an individual's community participation skills, living situation, caregiver needs, and desired services. These questions were designed by the Registry (Wait List) Ad Hoc Committee (a community stakeholder group), and SDS remains committed to including community input before the questions are changed or updated. Answers to questions on the DDDR also provide projected timeframes for the need of a particular service. The DDDR attempts to measure the immediate needs and circumstances of everyone on the Registry and weigh those needs against the needs of all applicants.

The DDDR can be completed by any applicant, their Developmental Disabilities Resource Connection (DDRC) provider, Care Coordinator, or designated representative, using the online form available through the Harmony data management system, or by completing the paper form and mailing or faxing (SDS will accept by email only if submitted using secure HIPAA-compliant email) the completed form to SDS.

Scoring Criteria used for Managing the Registry

Once a completed DDDR is received, each question on the DDDR is reviewed and scored by a Qualified Intellectual Disability Professional (QIDP) within SDS. After scoring by a QIDP within SDS, a person's DDDR total score is tabulated electronically using the Harmony system. The applicant or their legal representative is notified in writing of their placement (score) on the Registry. If an individual's life situation changes, a revised DDDR may be submitted to SDS at any time. The Registry (Wait List) Ad Hoc Committee developed the current form in use and assigned a weighted set of possible scores to each question. The form uses a numerical assessment of need; consequently, the higher the need, the greater the number of points that are given. A written explanation of the scoring system is available on Senior and Disabilities Services' website and a paper copy can also be provided upon request.

An individual's standing or rank on the Registry is relative to the scores of all the other individuals on the list. Consequently, an individual's position on the Registry may change depending on the relative needs of others on the Registry. Individuals receive a copy of their scored submission each time a new DDDR is received and scored by SDS.

Selection Methodology for Removing Persons on the Registry

Alaska's IDD waiver, as approved by CMS, allows 50 individuals a year to be "drawn" from the Registry. Thus, SDS "draws" monthly the four highest-scoring individuals for the HCB IDD waiver. The selected individuals are notified via certified mail of the opportunity to possibly utilize HCB waiver services. This notice includes information about the Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) Level of Care (LOC) process.

Once the ISW reaches the 600-person capacity approved by CMS, individuals interested in the waiver will be placed on an ISW Registry until an opening becomes available. When this occurs, a separate report will be developed.

**Section 3: Basic Demographic Information
(AS 47.80.130(d)(3))**

The following demographic information represents the status of the Registry population during the State of Alaska fiscal year beginning July 1, 2019 through June 30, 2020. Since the Registry is constantly being updated, this data represents the specified time period and may not reflect the current state of the Registry. The historical demand for services reflects minimal variance in population, geographic distribution, and services requests over time. The following data was taken from the Harmony data management system:

Number of individuals on the Registry as of 6/30/2020:*	765
Number of individuals 22 years old or younger as of 6/30/2020:	521
Number of individuals on the list for 90 days or more:	686
Average length of time for individuals currently on the Registry**:	50 months

*When an individual requests placement on the Registry they can indicate an interest in being considered for the ISW, IDD waiver, or both waivers. Individuals selected for the ISW often choose to remain on the registry for consideration for the IDD waiver. The number of individuals on the Registry significantly increased as the State used it as the entry point for the newly approved ISW. **It is important to note, when reviewing the numbers reported here, that 410 individuals who remain on the Registry have been selected for the opportunity to apply for the ISW.**

**Note that while the average length of stay on the Registry is currently estimated at over four years, many of these individuals have very low scores because they are receiving early intervention, school supports, or other community services. They may be on the Registry for an extended period because their need for expanded supports is not acute.

Age Range	Number of Individuals	Percentage
0 to 3 years of age	21	3%
4 to 17 years of age	354	46%
18 to 21 years of age	115	15%
22 to 64 years of age	269	35%
Over 65 years of age	6	1%
Total	765	100%

Gender	Number of Individuals	Percentage
Male	504	66%
Female	261	34%
Total	765	100%

Race & Ethnicity of Individuals on the IDD Registry

Ethnicity	Number of Individuals	Percentage
Alaska Native	148	19%
Asian	44	6%
Black	26	3%
Hispanic	8	1%
Pacific Islander	17	2%
White	254	33%
Other	268	36%
Total	765	100%

Geographic Distribution of Individuals on the IDD Registry by Regional Service Area

IDD Service Region	Number of Individuals	Percentage
Anchorage/Mat-Su	467	62%
Interior	44	6%
Northwest	15	2%
Gulf Coast	95	12%
Southeast	80	10%
Southwest	57	7%
Unknown	7	1%
Total	765	100%

**Section 4: Needs, Preferences, and Estimated Cost to Serve Individuals on the Registry
(AS 47.80.130(d)(4))**

One of the functions of the DDDR is to gather information on the services individuals feel would best help them be in the most inclusive community setting. This data allows the state to project the cost of serving these individuals. Most people on the Registry request more than one service, although there are some who have not requested specific services.

Projected Annual Cost

The following annual cost projection represents Senior and Disabilities Services’ best estimate to serve all the individuals on the Registry who indicated a service need(s), with the assumption that they would be served in the Medicaid Waiver program. Not all individuals on the Registry will be eligible for waiver services. Of the 59 individuals drawn for the IDD waiver over 68% have active waivers in place, 8% have been closed, and the remaining are in progress. There are many reasons why individuals do not move into waiver services after being pulled from the Registry and offered the opportunity to proceed. For example, they may not qualify for Medicaid, they decline participation, they leave the state, or they do not meet the necessary level of care (ICF/IID) to qualify for waiver services.

The Medicaid Waiver program reimbursement rates provide the most accurate cost data upon which to base budget projections. Care coordinators create, and SDS approves, support plans that are tailored to meet an individual’s needs. The average costs listed in the following table are based on FY 2020 payment data. These payments do not account for costs associated with provider capacity-building and infrastructure development for requested services. There are some service characteristics pertaining to payment amounts that are worth noting:

1. The Residential Habilitation rate represents an average of the costs for all of the sub-categories that fall under this service definition (e.g. Family Habilitation, Group Home, In-Home Supports, and Supported Living).
2. Respite cost estimates are based on the maximum allowed amount of service, and therefore represent a liberal estimate of the average total cost to provide these services.
3. The average cost of Care Coordination assumes that an individual receives this service for 12 months.

Type of Service Requested	Average Annual Cost per Person	Number of Requests	Projected TOTAL Cost*
Family Habilitation	\$36,115.36	96	\$3,467,074.48
Group Home	\$110,566.41	164	\$18,132,891.46
In-Home Support	\$16,343.03	556	\$9,086,726.41
Supported Living	\$44,363.78	275	\$12,200,039.23

Total Cost for Residential Habilitation Services			\$42,886,731.59
Respite	\$6,993.93	643	\$4,497,095.92
Supported Employment	\$15,767.12	335	\$5,281,984.11
Day Habilitation	\$15,972.98	712	\$11,372,761.10
Care Coordination	\$2,836.77	724	\$2,053,819.98
Intensive Active Treatment	\$4,332.37	333	\$1,442,678.56
Transportation	\$2,610.24	427	\$1,114,574.18
Environmental Modification	\$13,587.33	158	\$2,146,798.67
Total Cost			\$68,649,645.43
Estimated Total State Cost with FMAP at 50%			\$34,324,822.72

*The data for the average cost per individual is derived from COGNOS, a reporting tool for the Alaska Medical Assistance Health Enterprise. SDS's data source for the number of individuals on Registry who are identifying their need for specific services within the next two years is Harmony. FY2020 costs are preliminary at the time of this report, as providers have 12 months in which to bill for services rendered; future reports may show different total costs for these services as more provider claims are submitted for payment.

**Section 5: Number of Individuals Selected or Removed From the Registry
FY2020
(AS 47.80.130(d)(5))**

Reason for Removal	Number of Individuals
Selected for waiver services	59
Non-responsive to request for information**	210
Not eligible for DD services	6
Total	273 (distinct count)

** It is the responsibility of the applicant to keep SDS informed of current contact information. If someone is selected from the Registry for waiver services and fails to respond to the notification letter, they can be removed from the Registry. Applicants can be placed back on the Registry, with submission of a new DDDR.

For the 59 individuals removed from the Registry during FY 2020 (7/1/2019 – 6/30/2020) for the reason of “selected for the waiver” the average number of months on the Registry (number of months from first application to removed date) was 29 months.

For all 273 individuals who were removed from the Registry during FY 2020 (all reasons, not just selected for waiver) the average stay was 42 months.

**Section 6: Number of Individuals on Registry for More Than 90 Days and SDS
Review Process - FY2020
(AS 47.80.130(d)(6))**

Of the 765 individuals who were on the Registry during FY20, 686 were on for more than 90 days. The average length of time of those removed was 42 months. As of 6/30/2020, 25 individuals, or 3%, had a reviewed total score of 0.

SDS takes steps to regularly review everyone's status while waiting for services or supports. Through community providers, families and participants are reminded they can update their profile as many times as needed. SDS attempts to regularly send notices to participants who have not updated their profile in the last 12 months.

Additionally, SDS attempts to update participant's eligibility status as identified in their original DD eligibility determination letter. If a participant does not reapply for services or is determined DD-ineligible they are removed from the Registry.

**Section 7: Number of Students with Developmental Disabilities in Special Education
(AS 47.80.130 (d)(7))**

Special Education provides specially designed instruction in a school setting. Local education authorities, under the regulations and statutes of the Alaska State Department of Education and Early Development (DEED), administer these programs. This is in contrast to IDD Waiver Program services, which provides for services and supports in the home or community to assist the individual and their family to participate in community life and avoid institutional placement. IDD Waiver Services are administered under the Department of Health and Social Services statutes and regulations.

Another key distinction between special education and the IDD Waiver program is that, for those who qualify, Special Education is an entitlement; but the IDD Waiver Program operates within the limits of annual legislative appropriations and the capacity of the state and community to provide the desired supports.

According to DEED, as of **October 1, 2019** (latest available DEED data) about 19,473 students aged 3 to 21 are receiving Special Education services. Among these Special Education students, approximately 2,473 may have developmental disabilities. Individuals with the following types of developmental disabilities may be receiving special education services across the state: Intellectual Disabilities, Cerebral Palsy, Autism, and Seizure Disorder. Similarly, children with other conditions or presentations may qualify as having a developmental disability if they experience substantial limitations in three functional areas. (Alaska Department of Education and Early Development. Special Education Child Count by District. Retrieved from <http://education.alaska.gov/stats/>)

**Section 8: Copies of Reports, Policies, Manuals, and Procedures
(AS 47.80.130 (d)(8))**

Copies of this report and the forms used to manage the IDD Registry are available on the Website of the Division of Senior and Disabilities Services at:

<http://www.hss.state.ak.us/dsds/dd/default.htm>

Copies of this report, policies, and forms used to manage the Registry may also be obtained by requesting them from the Senior and Disabilities Services at the following address or phone number:

**Senior and Disabilities Services
1835 Bragaw St., Ste. 350
Anchorage, Alaska 99508
(907) 269-3666
or
Toll Free at 1-800-478-9996**

Additional Information/Attachments

AS 47.80.130 (d) Powers and Duties of the Department

(d) When state funding is not adequate to meet service needs, the department shall establish a waiting list for persons with developmental disabilities who would be eligible to receive state-funded services under [AS 47.80.100](#) - 47.80.170 if adequate state funding were available. The department shall, on an annual basis, review the waiting list and submit a report to the governor containing the information required under this subsection. The department shall send a copy of the report to the persons chairing the house and senate finance committees and the persons chairing the house and senate health, education and social services committees and shall notify the full legislature that the report is available to all legislators. The report must:

(1) describe the purpose for the waiting list and the strategies used to notify persons about the waiting list, and must include a copy of the information used by the department to inform individuals and families about their rights and responsibilities under [AS 47.80.100](#) - 47.80.170;

(2) explain how an individual is placed on the waiting list, what criteria determine rank on the list, and how the waiting list is used to select individuals equitably and fairly across the state;

(3) give the basic demographic information across all regions about the age, sex, and racial and ethnic background of the individuals on the waiting list;

(4) identify the level of need and preferences of the individuals and families on the waiting list for the services and the supports that may be necessary to meet their needs and project an annual cost to meet this need;

(5) identify how many individuals were removed from the waiting list during the 12 months covered by the report, why they were removed from the list, and how long the individuals had been waiting for services or supports before they were removed from the list;

(6) list the number of individuals who have been on the waiting list for 90 days or more with an account of the department's steps to regularly review each individual's status while waiting for services or supports;

(7) report annual data from the Department of Education and Early Development about the number of students in special education with developmental disabilities graduating from high school, dropping out of high school before reaching age 22, or reaching age 22 without graduating from high school; and

(8) indicate that written or electronic copies of policies, manuals, and procedures used by the department to implement [AS 47.80.100](#) - 47.80.170 are available.